

Testimony in Support of HB 5432

An Act Expanding Health Insurance Coverage of Specialized Formula for Children with Eosinophilic Disorders

Insurance and Real Estate Committee

February 19, 2013

Thank you for the opportunity to testify in support of House Bill 5432 to expand coverage of medical food.

My name is Lisa Rana, and I am a mom of a child with EGID and I am all about common sense approach to things. My son Ehsan Rana is diagnosed with EGID, he is 7 yo and has struggled with his disease since he was ~1 yr old. My son was in the NICU for about 1 month after he was born for feeding reasons. Once we finally got to bring him home, we thought he was through the worst of it, unfortunately that was only the beginning. Then began our real struggle, we had no idea how our lives would be changed forever. Not being on a growth chart, vomiting daily multiple times, and never wanting to eat was his new normal.

I want to show you a couple of pictures of Ehsan before his G-tube was place. 1st one was our family, Ehsan is asleep and is smaller than his baby brother who was 8 months old at the time. He was sleeping as he always was due to his severe malnutrition. I want to show another picture, where you can see grey hair on his head, the grey hair was a result of lack of melanin in the hair follicle directly related to malnutrition.

I am here to tell our story in hopes of changing the outdated CT law, as well as increasing awareness of this very important issue.

When Ehsan was diagnosed with EGID we really had no idea of what it meant, all we knew is that we struggled daily multiple times a day to try and get our son to eat and pray he would hold in what we fed him. Since he had severe food allergies on top of his EGID, we were very limited to what we could feed Ehsan. We went to a GI MDs at CCMC here in Hartford and they recommended that he needed and amino acid based medical food (Elecare). So we tried to get him the formula. I was denied by the insurance company and then appealed the decision. My goal was to get him to drink his medical food at an early age so he gets used to it (the formula is very unpalatable and has a severe aftertaste) then maybe he would not have to have surgery and a G-tube placed.

The appeal process took many months of constant documenting and contacting people at the insurance company, each day was a day that Ehsan was losing weight, and getting sicker. I was informed that I was denied and that his formula would not be covered despite all my efforts. In the same conversation as I pleaded with the woman, she stated this to me 'Maam if you just put a G-tube in your son the medical food (Elecare) would be covered' These are words I will never ever forget. I thought how completely

ridiculous, again I am all about common sense. So why is it that I need to have my son go through another life threatening major surgery, (he had other surgeries related to his EGID) as well as the cost of all the associated medical supplies, tubes, pumps, syringes, and tubing needed for the feeds etc. Not to mention the psychological effects with not being a normal child. How does that even make financial sense for an insurance company? Well unfortunately despite my daily struggle to get him to eat and hold down anything, it actually became a medical emergency to insert a G- tube into my son. I remember this day vividly, both my husband and I cried, this was when we truly accepted that our son has a life threatening disease that he would never outgrow.

So he began tube feeds, a side effects of tube feeds is of course severe nausea and vomiting but the premise is to expand his stomach, get it used to the medical food so the child can get proper nutrition and grow to be healthy. So he was on a pump for about 1 year. He quickly began growing, having energy and was thriving.

I could not get over the fact that Ehsan had never really learn to eat, he never met any feeding milestones and still would not tolerate any food near him let alone eat it. Food was a complete aversion to him. At this time I decided to seek out an intense feeding program that would help him get comfortable and not be afraid of food, with the hopes that he would self feed himself foods that were safe for him. We chose the feeding program in PA with proven success to help kids get off tube feeds and be independent with eating/drinking. Again we were denied coverage for the feeding therapy. So more delays, these delays directly and adversely affect the child from obtaining appropriate care. So again I ask -why would an insurance company not want to pay for a therapy that is proven to work and teach a child to drink their medical food and learn to eat regular foods that are safe for them? The insurance company would not have the costs of the pumps, and associated medical supplies, thus no need for surgery or a G tube.

My husband and I were adamant in our search to help make our son learn to cope with his disease and be as "normal" as he could be from an eating perspective. After over 4 mos of continued appeals from myself, again hours spent on documenting the cost benefits, they finally agreed to the intense feeding therapy. We spent 5 weeks in the program working everyday to help Ehsan learn to eat something and feel comfortable with food. It was a difficult period, but proved successful, by the end of the therapy Ehsan had learned to eat ~ 18 foods. It was small amounts, and bites due to his disease but nonetheless he was eating real food for the first time!! He currently learning to drink his medical food (Elecare) during the day. He is still reliant on his medical food and anything else he eats are "bonus" calories.

So you ask why we are here today? If we can prevent just 1 other family or child from going through what we have for the past 7 yrs then I have been successful in outlining the daily struggles of the children and their families who are affected by this disease.

In closing it is imperative to acknowledge/recognize that EGIDs as a real and growing disease. It is a disease that could be compared with diabetes. If a diabetic child does not get there insulin they would die. Who in this present day would deny a diabetic child

their insulin? The answer is no one. The same hold true for EGID and medical food. Medical food is the only treatment for EGID and therefore should never be denied. Here in CT we are not current in our medical food law. We need to ensure that these children are taken care of beyond 12 yo, which according to the current CT law is when coverage is no longer mandated for medical food. Therefore the age limit for medical food should be increased.

Would we really deny children the right to live happy and healthy lives? Thank you. I can take questions.

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